Consent in the context of genetic information: Does it really only belong to you?

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“Genetics isn’t just about you. It’s about your family, too.” -- 23andMe

Remember the Cambridge Analytica scandal, when Facebook allowed some people’s personal data to be passed to an app called “This Is Your Digital Life” without their consent? Were you one of those people who got a notification that some of your personal info were compromised—not because you yourself ever used the app, but because one of your friends did? Do you remember that feeling of violation, that someone who you trusted enough to be connected with on social media had
unwittingly chosen to download that disreputable app, and thus put your information at risk as well as their own?

Now, imagine that something like this happens again, but this time, it’s a closer connection, and the data are much more sensitive—the data that make you who you are, that is the most essential component of your person—your genetic sequence.

Let’s break down that phrase “Your Genetic Sequence.” And let’s start with the genetic sequence part in the context of companies offering genetic testing.

Currently, most companies offering genetic testing use genotyping methods, not full sequencing. Genetic sequencing refers to the process of decoding the entire sequence of an individual’s genetic information, whereas genotyping looks at specific segments of your genetic information for markers associated with specific groups of people. That is, if your genetic information were a book, sequencing would mean reading every single word of the book in order, whereas genotyping would be scanning for a specific combination of words, regardless of where they appear or the other words in the book. You could tell that the book was from the Harry Potter book series if you read every word, but you could probably also figure that out just by noticing that the words “Harry,” “Potter,” and “Wand” appeared in the text. You may not be able to tell if you were reading Harry Potter and the Half Blood Prince or Harry Potter and the The Sorcerer’s Stone, but you’d be pretty confident that it came from the series. The more words you scanned, the more likely you would be to identify the specific book you were reading or, in our analogy, the specific person to whom the genetic sequence belongs.

One reason companies genotype rather than sequence is that it is currently too expensive to fully sequence every sample. However, the cost of sequencing is decreasing at an extraordinary rate; in 2001 the cost to sequence a single genome was $100M; in 2007 it dropped to $10M; and in 2017 the cost was a mere $0.1M! That is a 1000 fold drop in 10 years. Based on a communication with a 23andMe customer service representative, we learned that the company stores your sample for up to 10 years. If current trends continue, the cost of fully sequencing samples will be cheap enough that pulling your genetic sample out of storage to sequence it will not only be be feasible, but also economically desirable.

Now, back to the phrase “Your Genetic Sequence”, let’s consider the most important word—“Your”. Consider two potential scenarios: the hacking of a bank’s database vs. your personal account credentials being stolen. The bank’s database links millions of users to their passwords, exposing much more than just your personal account. “Your” genetic information is not that different, because your genetic information links you to everyone who is related to you. How large of an effect this might have on them depends on how closely you are related. You share ~50% of your genetic information with your parents, your siblings, and your children; ~25% with your grandparents, cousins, aunts and uncles. If you have an identical twin, ~100% of your genetic information is shared. This really calls into questions whether your genetic information is truly yours to sequence. **According to reports by companies that offer genetic testing, results that reveal false parentage, infidelities, and other such surprises are common enough that these companies are training dedicated customer-care specialists to speak with individuals confronted with shocking surprises ([https://www.theguardian.com/lifeandstyle/2018/sep/18/your-fathers-not-your-father-when-dna-tests-reveal-more-than-you-bargained-for](https://www.theguardian.com/lifeandstyle/2018/sep/18/your-fathers-not-your-father-when-dna-tests-reveal-more-than-you-bargained-for)).**

Admittedly, it’s nothing new that genetic or health information is sensitive. This has been true for some time. But, what’s different now is that suddenly it is feasible for companies to purchase huge amounts of personal data and make automated decisions on the basis of those data and, in the
future, the same sort of tactics could be applied to genetic data.

Well, so what? If you’ve followed some of the cases where criminals were arrested years later based on DNA on genealogy sites (https://www.npr.org/sections/thetwo-way/2018/04/26/606060349/after-arrest-of-suspected-golden-state-killer-details-of-his-life-emerge), you might be tempted to push back, saying, “it’s actually a great thing that we can now solve open murder cases.” But, even if you’re sympathetic to the desire for answers, there may be serious consequences—even for those of us who may not be concerned about run-ins with the criminal justice system.

As science progresses, we are getting better and better at predicting health and behavioral outcomes from genetic information—which, in a lot of ways, is really great news for the potential of these new techniques to help cure diseases and improve lives. But at the same time, these new possibilities may have scary consequences. What if your genetic information shows a risk marker for a genetic illness, and suddenly your health insurance cost goes up? What if your mother elected to sequence her genetic information, which showed a risk marker that led your health insurance costs increasing due to the likelihood that you inherited that same risk marker? What if a potential employer refuses to hire you for a high-pressure job because your medical records indicate a predisposition to heart disease? We are all used to our own actions having consequences, and probably aren't surprised when our car insurance goes up after getting into an accident. But how would you feel if the actions of someone close to you affected you? Recall the Cambridge Analytica scandal?

One of the scariest things about it is that we have no way of knowing what kinds of things will transpire with people’s genetic and health data 50 or 100 years into the future, but right now people are happily giving companies like 23andMe and Ancestry.com full access to their genetic data—which is also their relative’s genetic data (including those who have not yet been born!). These helpless relatives cannot stop their family members from signing away information that affects them without their consent and without recourse.

We have focused a lot on potential risks, but it is important to highlight that there are many good reasons to get genetic testing and stifling innovation at this stage could have devastating consequences for developing new and targeted therapies. There are already treatments, such as for cancer (https://www.cancer.gov/news-events/press-releases/2018/tailorx-breast-cancer-chemotherapy/), that are specific to patients based on their genetic profile. These personalized treatments hold great promise for more effective care and for reducing health disparities.

Nevertheless, it is important to weigh the benefits and risks and carefully consider what data to share and who to entrust with it. Volunteering data for a National Institutes of Health study is very different than swabbing your cheek so that a private company can tell you what percent Irish you are and potentially store your information for a decade.

The case of genetic data raises new questions about who should be allowed to consent for data sharing—and whose consent should be necessary for a single individual to elect to share their genetic data. More broadly, it calls for a need to think about who should be involved in shared decision-making around these issues. Maybe—at least for purely curiosity-driven motivations—the answer is no one can truly consent to sharing genetic information. Because it’s never just your genetic information.

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